

White Paper Report

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“Digital Histories of Eugenic Sterilization: Developing
a Multi-Modal Prototype and Best Practices for Sensitive Health Data”

Humanities Collections and Reference Resources, Foundations Grant,

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Introduction to *Eugenic Rubicon* and the history of eugenics in the United States

During most of the twentieth century, eugenics was a popular “science” in much of the world that included both a “positive” or softer side and a “negative” or harder side. Genetic determinism undergirded both “positive” and “negative” eugenics although the former allowed greater latitude for environmental factors. From the 1900s through the 1960s, both variants of eugenics influenced policies and attitudes on local and national levels in the United States. One of the most dramatic ways in which eugenics affected Americans was through policies and practices of surgical sterilization.

Many people are surprised to learn that in 1907 the Midwestern state of Indiana passed the world’s first sterilization law, which authorized medical superintendents in homes and hospitals to sterilize people whose deleterious heredity appeared to threaten society. From this first law in 1907 to 1937, 32 U.S. states passed eugenic sterilization laws, which were used to control the reproduction of vulnerable populations until the 1970s, when legislatures started to repeal these statutes. Over the period of about six decades, over 60,000 sterilizations were officially recorded, principally in state homes and hospitals for the feeble-minded and mentally ill.

The broad contours of eugenic sterilization and coercive eugenics in the United States are familiar to many scholars and it is not uncommon for eugenic sterilization to be held up as an egregious example of pseudoscience. Yet we still know very little known about the demographics and experiences of people sterilized. Working with a unique resource -- 20,000 sterilization recommendations from California institutions from the period 1921 to 1952 -- our project sought (and still is working toward this goal) to make the history of eugenic sterilization visible, accessible, and interactive through the creative and integrated use of digital platforms,

big data analysis, data visualization, and digital storytelling. These records were microfilmed by the California Department of State Hospitals in the 1970s and discovered by Stern in 2007; she and her team of colleagues at the University of Michigan digitized these reels and have been using them in compliance with state and university regulations to create a de-identified data set.

Unlike many digital archive projects, by law we simply cannot make a portion of the digitized records available to the public; we are required to maintain patient privacy even as we work to provide access to this important history of reproductive coercion and institutional control. In addition to the legal restrictions on a portion of the archive, there are important ethical considerations for many of the materials in the collection, including medical records that are no longer governed by HIPAA regulations. Our work continues to advance public knowledge and access to these materials while also protecting the rights of the individuals who were harmed.

With the support of the NEH HCRR Foundations Grant, we have been able to undertake two years of intensive work that has substantively advanced the *Eugenic Rubicon* project. For the Foundations phase of the *Eugenic Rubicon* project, we proposed to create a website to house the following items, which were also to be created or refined during the grant period: a contextualized set of primary sources, secondary and tertiary scholarly narratives, and an anonymized integrated data set, along with data visualization, GIS mapping, and digital storytelling. In addition to greatly expanding access to these otherwise scattered and relatively inaccessible materials, this project sought to innovate in terms of best practices for dealing with sensitive data sets that are of historical and public interest.

The project proposed two major outcomes, both to be housed in an innovative digital resource: 1) guidelines for best practices around the digital uses of protected health information,

that are sensitive to the tension between the “right to know” and the “need to protect” and 2) a digital prototype that simultaneously utilizes technical tools well-tuned to sensitive health data, humanizes the experiences of sterilized patients whose stories are contained in the records, and incorporates data visualizations that can illustrate social and institutional patterns across time. Given these aims, our project is unique insofar as we have been concerned with both the technical and regulatory aspects of data sharing, and the potential for digital storytelling as a way of humanizing and contextualizing sterilization experiences in the 20th century.

In order to accomplish this work informed by insights from leading scholars in fields such as Digital Humanities, History of Medicine, Archival Studies, and Science Studies, we held a productive workshop with experts in fall 2016. Over the course of the grant period we have developed two interlocking prototypes for a digital resource on eugenics and sterilization in California. In summer 2017, we conducted four intensive usability studies with distinct sets of users in northern California. We have presented and written widely on the project for public audiences as well as for academics in the aforementioned fields. This white paper provides brief descriptions of our accomplishments and concludes with a concise discussion of our plans for the implementation phase of the project

Evaluation

We had several successes over the course of this project. First, we intertwined prototypes that allowed us to work and collaborate from a distance and with different technologies. Second, we received valuable feedback from a range of users, providing valuable guidance for the next iteration of this project. Finally, it became clear as we shared the project, that is appealing to

multiple audiences, and has the potential to make accessible histories of eugenics, particularly with regard to those affected by sterilization, through a multimodal site.

At the same time, we did have challenges. As our expert workshop demonstrated, there is disagreement across disciplinary fields about what constitutes appropriate use of sensitive materials. We believe this set of disagreements pivot around a generally unresolvable tension between “the right to know” and the “need to protect.” HIPAA and confidentiality structure the legal issues related to the sharing of sterilization documents, but there are bigger ethical questions that require further engagement (and that we begin to address in the white paper). What is more, we found ourselves subject to a shifting legal and institutional landscape with respect to the records themselves. When Stern found the California records in 2007, they were under the purview of the Department of State Hospitals and had to be used in accordance with HIPAA regulations. Then in 2016, the records were transferred to the California State Archives; in so doing, their status shifted from being medical records to historical documents. As such, they are no longer subject to the rules of the California Committee for the Protection of Human Subjects, and are instead protected through the California Code related to historical health records. The pertinent California Code states that all documents 75 years and older are completely open access and can be used in their entirety and documents less than 75 years old should be de-identified. This means that different legal paradigms govern portions of the records and that the institutional context for the materials has changed even as we were developing our resource. This was an excellent reminder that archival materials are not static. At the same time, despite the change in public accessibility for the records, we, our users, and other scholars working in these areas are acutely aware that the history we are recovering is a living one, even if the people represented in the documents are themselves no longer alive. Accordingly, in

addition to the changing legal status of the materials, we attend to the more general ethical concerns, such as considering unintended consequences when making unredacted material widely available on the internet.

This caution and care reside alongside a clear sense from our usability studies that the story of eugenic sterilization in the United States deserves to be remembered and told, and the particulars of the California context discussed. Our users were eager for more material and enthusiastic about future use, but wanted more frames and tools to guide them through the materials and situate them in time and place. We learned a great deal from the usability studies we conducted testing the first iteration of the prototype. That, in turn, informed our second iteration of *Eugenic Rubicon*, and has shaped our implementation grant proposal. The summary report of that work is included in appendix C. Among the key takeaways were that many of the users in our study hoped to incorporate the site into curriculum for secondary students (grades 6-12). We were pleased that the majority (88%) found the site to be appropriate for that age group. That said, about a third of respondents signaled a need to further refine the materials to provide context and content appropriate to a more general audience and respondents had several requests for more depth and detail about the daily lived experiences in the facilities covered by the project. Respondents appreciated that materials were presented in a variety of formats and media types and asked for further expansion of that variety. Some users reported challenges with navigating the site, and the interlocking pair of sites was predictably challenging for some. The two sites we created need to be integrated and replaced by a new site; although we like many aspects of Scalar, ultimately the book-style format does not allow for the multimodal design we hope to achieve in the expanded iteration.

The overriding message we received from users is that we need to develop contextual framing so that users can become aware of what resources can be found in the digital sites, and be guided constructively to find them. In addition, some users were interested in the possibility of more interactive tools. For example, the disability advocacy groups, some of whose members had been institutionalized, wanted avenues to tell their stories, and relate them to the broader histories captured in the digital sites. In this sense, there is potential for interactivity and crowd-sourced knowledge, yet the ethical issues raised above, about sensitive health stories and the pain and trauma associated with sterilization and institutionalization, must be taken into consideration.

Public response to the project has been robust, with 714 unique users for the second iteration of the site (over the period 6/1/2017-9/1/2018) and 1,400 unique users for the first iteration since launch. In total we have had more than two thousand unique users engage with the two prototypes. Just over half of those users come from North America, but we have seen a global reach for the project with more than 200 users in the U.K. and Western Europe as well as smaller cohorts from Brazil, the UAE, and Iraq among other countries. To date, slightly more than fifty percent of our users for both sites are under the age of 35 and we have about 20% of our total usage coming from repeat visitors, which suggests that a portion of our users are finding the site useful for prolonged exploration.

In terms of media coverage, both Wernimont and Stern have taken advantage of multiple interview and speaking opportunities that demonstrate public interest in the project and success for the pilot in particular. This has included interviews with local and national public radio, *The Huffington Post*, *The Atlantic*, *Sounding Out*, *The State Press*, and *Zócalo Public Square*.

Continuation of Project

To continue this kind of public engagement and to further develop our prototype into a full-scale implementation, we applied for an American Council of Learned Societies (ACLS) Digital Extension grant in 2016 and will be submitting a revision to that application for the 2018/2019 cycle. Additionally, we applied in 2018 to the NEH HCRR program for an Implementation Grant to continue this project. Throughout we have continued to develop our network of users and experts in order to get additional feedback on the site usability and content relevance.

Long Term Impact

During our session with the grade 6-12 teachers in 2017 several educators indicated an interest in using materials from *Eugenic Rubicon* in teaching history classes. We have an open invitation from Milton Reynolds to present again at the Teaching History, Teaching Ourselves workshops in coming years and we will continue to look for opportunities to share this resource with educators both within higher and secondary education contexts. At Michigan, graduate and undergraduate students have worked on the sites as part of Stern's research lab; thus, this project has served as a kind of practicum for training studies in the history of medicine and digital humanities.

Usage of the new iteration of the site continues to be robust with an average of 55 new users in each of the last three months, which suggests to us that users continue to find and utilize the resources therein even during "quiet" periods when the news and publicity cycles are not as active. If our implementation grant is funded, we will be able to expand the digital archive to include materials from North Carolina and Iowa, and create a site that can share the histories of

more than one half of the people sterilized in the United States under eugenic laws in the 20th century. We suspect that the cross-state data and comparisons among the states, which will highlight the themes of race, gender, age, and disability, as well as legal issues such as consent and coercion, will be appealing to a broader array of audiences, and at a more national level. It should be noted that when Stern has presented on this project internationally (in Germany, France, and England) there has been enormous interest in this history and in our project as an innovative contribution to digital humanities.

Award Products

The major products of this award are the interlocking prototypes and the white paper. The first of the prototypes, spearheaded by Jacqueline Wernimont, was built in Scalar (2nd iteration: <http://scalar.usc.edu/works/eugenic-rubicon-/index>) and has gone through two iterations based on feedback from users and experts. The second is a bespoke site (2nd iteration: <http://ec.ac.lsa.umich.edu/>) built using a variety of mapping and sequencing tools, which has also been through two iterations over the course of the first year. The Scalar site provides scaffolding for the project as a whole and explores five different aspects of eugenics in California. The second can also act as a standalone site, and provides an in-depth exploration of the Sonoma State Home where more than 5,000 sterilizations were performed in the 20th century. Both sites can incorporate additional data visualization, interactive tools, and digital storytelling, and we continue to acquire and upload both text and visual assets into these resources.

Additionally, as part of our work to educate the public Stern and Wernimont have spoken on this project with local and national media outlets, including interviews with local and national public radio. During the grant period, our project received a great deal of media coverage, and

popular articles written by Wernimont and Stern were circulated in social media. In the 2017 piece, [“Remembering Sara Rosas Garcia,” written for the *Process* webzine of the Organization of American Historians](#), Stern offers an example of the kind of contextualization and digital story-telling that we intend to incorporate into the expanded version of *Eugenic Rubicon*. Additionally, Stern has written and been interviewed extensively in public venues, including for *HuffPost* (January 2016), *Zócalo Public Square* (June 2016), and *The Atlantic* (January 2017). Wernimont has offered several invited talks and installations based on this work, including at University of Iowa’s *Archives Against Amnesia* (2018) and Dartmouth College’s *Critical Digital Humanities Symposium* (2016) and published a piece in *Sounding Out* (2016) about some of our mixed media work during the prototype phase.

We intend to expand the white paper accompanying this final report into a peer-reviewed article that examines the complex issues surrounding the utilization of sensitive health data in digital projects. We intend to submit this article to a journal of digital humanities or medical history by late 2018.

Pedagogy

A significant number of our usability testing participants work in 6-12 education and many of our users are coming from higher education institutions. Accordingly, much of our future development will focus on improving the pedagogical usefulness of the site and the materials contained therein. This will serve not only the formal educational contexts of use, but also for general readers who come to the site on their own and are eager to understand the history of eugenics in the United States. With our second iteration of the site we improved flow and added in additional contextual information. We look forward to a full integration of the two

prototypes and further elaboration of contextual/teaching materials during the implementation phase of the project.

As part of this project, we have created an annotated bibliography of salient sources, which we are continually expanding (included at the end of this report). This way we keep up on key publications related to sensitive health data, archival materials, and health-related digital humanities. This resource, a scholarly by-product, also could be shared in *Eugenic Rubicon*, providing resources for further reading for interested users.

Long-Term Impact

As we were working on *Eugenic Rubicon*, Stern and her Michigan team published two articles in the *American Journal of Public Health* that 1) estimated the likely number of living sterilization survivors in California as of 2016; and 2) demonstrated that Latinos, particularly young Latinas, were disproportionately sterilized, at rates up to 59% higher of non-Latina/os. These articles received a good deal of media coverage and informed an effort to pass a bill in the California legislature to compensate survivors with lump-sum payments capped at \$25,000. California's compensation plan emulated successful efforts in North Carolina and Virginia; the latter state is still accepting applications for compensation. Ultimately, the proposed bill in California, while passing through the Senate and Assembly committee, did not succeed. It is probable that the same state senator who authored the bill (Nancy Skinner, Alameda County) will take it up again in the next legislative cycle. Over 30 advocacy groups supported the legislation and sent endorsement letters to key legislators and the governor's office.

Although the process connected to the compensation bill was not linked to our work on the digital archive, it certainly generated interest in the archive and its materials. In addition, due

to media coverage, at least 10 people whose relatives were sterilized contacted Stern and her team, and shared their stories, expressing an interest in making their experiences more widely available. Going forward, we will apply our best practices to considering how we might include this personal material in *Eugenic Rubicon*. Stern also heard from former employees of the Sonoma State Home, who were interested in telling their stories, sharing materials, including photographs, and ensuring that the local community was made aware of our digital resources. This unexpected wave of communication was moving and potentially enriching for *Eugenic Rubicon* going forward.

Best Practice Recommendations

An integral component of this project has been the creation of an ever-expanding bibliography on archival practices with respect to sensitive health data and histories of state-sanctioned injustice. When we began the project, we (perhaps naively) hoped to be able to conclude this phase of the work by producing a set of universal best practices for the use of sensitive material in digital publication. What we learned, however, both through the process of building and testing *Eugenic Rubicon* and through conversations with colleagues and invested community members, is that the notion of universal best practices is problematic when dealing with such information. Rather than establish a set of rules that cannot possibly address the particularities of a range of difference projects, including our *sui generis* archive, we found that we needed to work hard to calibrate our acquired expertise of the content and archive-making with the insights of users.

We concur with (Theimer 2011) that it is imperative for archive-makers to engage with impacted communities so that digital materials are meaningful for them. A project like *Eugenic*

Rubicon has the ability, as seen with the legislative efforts, to inform social justice. Yet, as Greene (2013) reminds us, “It isn’t the job of the archivist to lead the social justice crusade.” (p. 328). Even so, *Eugenic Rubicon* is not itself an archive in the traditional sense. It is a public interface between the primary documents and records held by the California State Archive and our users. Our role is to present compelling and contextualized materials that matter to history and to people’s lives. We draw inspiration from digital archive projects in Cambodia (Caswell 2010, 2013), that capture the history of the Bracero Program (Osorio 2005), and that document human rights activism in Chile during the Pinochet dictatorship (Strauss 2015). As the professional scholars creating and publishing the site we bear responsibility to our several communities, which include scholars, legislators, impacted individuals and groups, and the general public.

In terms of best practices, it is incumbent upon those creating newly public and accessible resources on such sensitive histories to address issues of possible individual or community harm. For example, individuals may have sequestered this painful history for cultural, family, or political reasons. While these documents are accessible to the public, the level of access afforded at the California State Archives is dramatically different from open access on the internet, where great accessibility can mean that communities and individuals may be targeted by those with malicious intent. Even in situations where no harm is intended, the openness of full web publication can mean that traumatic histories may be shared in ways that re-traumatize individuals and communities (Caswell, 2016). Such deliberations are examined by archival scholars such as Steven Bingo who notes that in considerations of access and privacy, “the archives should consider at least three factors: when the materials will be open to the public, the conditions under which the materials will be made available, and how those materials will be

presented to the public” (2011). In creating our digital resource we have sought to offer deep context for the primary documents collected therein and we have preserved the anonymity of those who were impacted by storytelling-at-a-distance with data visualizations, maps, and interpretive writing.

At the same time, that very promise of openness is part of what is attractive about digital publication. We agree with Jimerson that archivists, in our case digital archive-makers, should “use their power in determining what records will be preserved for future generations and in interpreting this documentation for researchers for the benefit of all members of society.” (p. 252). This power, however, is a privilege and is part of the complicated power differentials that often exist between institutional actors and impacted communities as Drake and Williams (2017), Christen Withey (2012), and Caswell, Cifor, and Ramirez (2016) have observed. Accordingly, we engaged Latinx, disability, and reproductive justice groups in the California area early and often. We have shared this work in scholarly settings, to be sure, but we have also consciously stepped beyond our university spaces in order to hear from our users about their needs, desires, and concerns. These conversations have all shaped our prototyping in this project and will continue to shape how we further refine and share *Eugenic Rubicon*.

Laws that were designed to protect privacy can also work to obscure historical and contemporary accounts of medical and reproductive mistreatment. In some of our usability studies we encountered individuals and groups eager to be able to search for family member information in order to fill in the gaps of personal history or to be able to raise awareness about these injustices. We seek, thus, to parlay between the specific needs of impacted communities, including their need to share and their need to protect, and broader societal interest in the history of eugenics and sterilization, the need, or at least the demonstrated desire, to know. Finally, we

have been influenced by the work of Bingo (2011) who, drawing from Nissbaum, argues that “privacy is not simply a question of which information is permissible to share, but more a question of how information is shared.” (p. 513)

Ultimately, our attention to impacted communities means one size does not fit all when it comes to data preservation and presentation. Rather, we can and will continue to work toward developing a set of best practices for *engaging with impacted communities*, which is the best way to understand how digital resource publication can balance the right to know with the right to privacy. Some principles from this practice include: engage early and often; make room for community members to participate in ways that are meaningful to them; consider “impact” widely in order to ensure that all stakeholders have a voice; and be prepared to change trajectory based on feedback. In addition to this white paper, we are working on a more fully articulated analysis of “best practices” and their roles in digital presentation and preservation of sensitive histories.

Specialized Bibliography

As part of our final products for this project, we have compiled a specialized bibliography for humanities and social science workers who are looking to publish and/or archive sensitive data in digital environments.

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